

American Indian/Alaska Native Health Research Advisory Council (HRAC)
Quarterly Conference Call
June 29, 2010

HRAC Tribal Delegates and Alternates

- Emily Hughes, Alaska Area Delegate
- Kathy Hughes, Bemidji Area Delegate
- Jim Crouch, California Area Alternate
- Elizabeth Neptune, Nashville Area Delegate
- Cara Cowan Watts, Oklahoma Area Delegate
- Stephen Kutz, Portland Area Delegate
- Chester Antone, Tucson Area Delegate
- Sarah Hicks, National Congress of American Indians Alternate
- H. Sally Smith, National Indian Health Board Delegate
- Andrew Joseph, Jr., Direct Service Tribes Advisory Committee Delegate

HRAC Federal Partners

- Wendy Perry, Agency for Healthcare Research and Quality
- Sue Clain, Office of the Assistant Secretary for Planning and Evaluation
- Ansalan Stewart, Office of the Assistant Secretary for Planning and Evaluation
- Leo Nolan, Indian Health Service
- Alan Trachtenberg, United States Public Health Service/Indian Health Service
- Wilbur Woodis, Office of Minority Health

Other Attendees

- Benjamin Smith, Indian Health Service
- Victoria Warren-Mears, Northwest Portland Area Indian Health Board
- Jill Mattia, National Institutes of Health, National Center on Minority Health and Health Disparities
- Dawn Houle, Tribal Self-Governance Advisory Committee/Indian Health Service

Meeting Minutes

- A quorum was reached on the call.

Call to Order and Introductions

- Introductions and facilitation: Cara Cowan Watts, Co-Chair

1. HRAC Updates

- Kathy Hughes (Bemidji Area) attended the National Indian Health Board's Public Health Summit on May 18-20, 2010 in Albuquerque, New Mexico and conducted a plenary presentation on behalf of the HRAC.
 - Kathy provided a quick overview of the HRAC and included the HRAC Annual and Research Reports as resources on the flash drive that was given to participants.
 - Cara asked what kind of feedback was received from the participants. Are they aware of the Council? Kathy responded that most did not seem to be

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aware of the Council, but she had some good discussions after the presentation and provided her business cards for follow-up.

- Sarah Hicks (NCAI) discussed NCAI's Mid-Year Session and Research Regulation & Data Ownership/Sharing Pre-Meeting that took place in Rapid City, South Dakota on June 20-23.
 - About 1100 people in attendance.
 - Held a Pre-Meeting on Data Ownership and Sharing at the request of the HRAC.
 - Victoria Warren-Mears was a speaker and shared a number of resolutions that will be posted on the NCAI Policy Research Center website.
 - The Tribal Scholar Forum was a successful event held in the morning with breakout session in the afternoon. Sarah thanked Chester Antone (Tucson Area) and Wilbur Woodis (OMH) for participating in the sessions.
 - NCAI shared their Tribally-Driven Research Agenda along with a brief survey consisting of 3 questions and a free t-shirt for participation. More than 400 people responded. This information will be compiled and shared with the HRAC.
 - Kathy Hughes was impressed with the responses received and suggested that we look at this when/if the HRAC decides to do another round of the Discussion Guide.

2. HRAC Priorities/Discussion Guide/Research Roundtable

- Kendra King Bowes (NAMS) informed the HRAC that the Office of Minority Health (OMH) committed extra funds for the HRAC in order to hold a Research Roundtable. The Research Roundtable will focus on what research is currently out there and what areas need to be researched more. The concept of the roundtable would be to bring together 4 HRAC Members; 4 Native Researchers; and 4 EpiCenter Representatives; and some of our federal partners. Then HRAC could present what has been identified as priorities at this point (from discussion guide results, HHS testimony, HHS recommendations, etc.) and get feedback on what specific areas need to be researched within the broad categories like cancer, diabetes, etc. Then this information would be brought back to HRAC for consideration and prioritization. NAMS has tentatively proposed to tag this meeting along with the face-to-face meeting scheduled for October 7, 2010.
- Chester Antone (Tucson Area) suggested that we do the Research Roundtable at HRACs next face-to-face meeting in October as it will give the HRAC more direction on what research to focus on.
- Sally Smith (NIHB) has been listening carefully to what is going on in Native Research. In Alaska, there have been 3 successful Native Health Research conferences. She posed the question: how do we bring in Native health researchers with the HRAC group? How do we as Tribal leaders incorporate the Native health researchers? What are their Tribal priorities and are they in line with HRACs?

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- Steve Kutz (Portland Area) commented that if the HRAC has researchers interested in a particular research topic, the HRAC could see if we can get research in those particular areas.
- Cara asked that Sarah, Sally, and Steve present a proposal to the HRAC on how we will do this.

3. HHS Regional Consultations and Advisory Committee Discussions

- Wilbur Woodis (OMH) expressed his excitement about the Research Roundtable. He suggested that when we hold our face-to-face meetings in Washington, DC we need to invite a lot of Federal officials to familiarize them with the HRAC. He asked if anyone else has any ideas on how to familiarize Tribal leaders with the HRAC?
- Jim Crouch (California Area) informed the HRAC that any activities related to the mandatory collection of data must follow health reform's new requirements. They must identify: race, ethnicity, language, disability, and LGBT status. He asked if the HRAC was doing anything to establish these new requirements.
- Wilbur responded by saying that the White House is doing this work.
- Jim Crouch suggested that the HRAC should put this on their radar screen.
- Cara suggested having another call on this issue and asked that he work with Kendra, Kathy, and she to get this arranged.

4. HRAC Charter

- Wilbur Woodis had hoped to provide an update as to where we are regarding the HRAC Charter, but we have not been able to move forward in this and we have not received clarification yet to our questions.
- Cara asked Wilbur what the HRAC has to do to close this issue. Must we write a letter to IGA?
- Kathy suggested writing a letter to IGA.
- Kathy Hughes (Bemidji Area) commented on how this issue comes up on every advisory committee she belongs to.
- Benjamin Smith (IHS) said that IHS has not had any issues with FACA as long as you have a written designation of authority.
- Cara asked that Kathy Hughes (Bemidji Area) and Sally Smith (NIHB) work on the Charter issue. Ben said he would email Kathy to share IHS' approach.

5. Federal Partner Updates

- Leo Nolan (IHS) informed the HRAC that he is frequently contacted by outside researchers. Most recently researchers contacted him about Multiple Sclerosis (MS) which is misdiagnosed in Indian Country. The researchers would like to form a cohort of American Indians/Alaska Natives (AI/ANs) but it would require that their blood be drawn.
 - This study is funded by the NIH and is being conducted by the Mayo Clinic.

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- Mr. Nolan asked what is the best way to ensure that the HRAC is involved in these kinds of studies. If the HRAC would like to participate in these studies, is there a main point of contact?
 - Mr. Nolan did receive some interest from the HRAC and said he would need something official and in writing.
- Wendy Perry provided some comments and discussed current activities of the AHRQ. There are two American Recovery and Reinvestment Act (ARRA) projects the AHRQ is currently involved in:
 - The AHRQ is advising IHS on extracting data for a longitudinal database to look at diabetes, cancer screenings, etc. over a 9 year period. Also, looking at comparative effectiveness research (CER) and the chronic care model.
 - They are also working on a different database for a CER study on Advanced Practice Pharmacists.
 - Chester Antone (Tucson Area) asked how he may follow-up on this study?
 - Wendy Perry (AHRQ) said she would put him in contact with the project person.

6. Other Business

- Andy Joseph (Direct Service Tribes) suggested that the HRAC hold a future call or discuss the Indian Health Care Improvement Act (IHCIA). He is particularly interested in long-term care. He thinks IHS will need help to figure out how to implement and research might be needed.
- Cara Cowan Watts (Oklahoma Area) responded by saying this was not an appropriate to discuss the IHCIA as the HRAC is to focus on health research.
- Chester Antone (Tucson Area) felt the HRAC should be able to comment on the IHCIA.
- Sally Smith (NIHB) suggested that the HRAC have a conversation with the national organizations as they are doing an analysis of the Patient Affordability Care Act.
- Steve Kutz (Portland Area) commented on what Andy Joseph asked. He posed the question: should there be any research done on delivery care models? Best practice models like long-term care?
- Cara Cowan Watts (Oklahoma Area) ended the discussion asking that Andy Joseph (Direct Service Tribes) write up his recommendations and Kathy and she would assist.

7. HRAC Meeting

- Kendra King Bowes (NAMS) asked HRAC members to respond on whether they can attend the October 7th face-to-face meeting in Albuquerque, New Mexico as we have not reached a quorum yet.
- Cara Cowan Watts thanked everyone for their time and reminded the HRAC of its purpose which is to focus on health research.